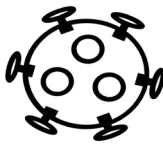


COVID-19

Information Guide for Parents Raising a Child with a Disability

July 30, 2021



Introduction

This COVID-19 information guide was created to address vaccine hesitancy within the disability population.

In July 2021, we surveyed parents raising a child with a disability to see why they were hesitant about vaccinating themselves and their child or adult that they are the guardian of.

The survey results showed that 29% of parents who were willing to get vaccinated themselves were hesitant about vaccinating their child.

Many worried about vaccine ingredients, were unsure of how the new vaccines worked, and were unsure of short term and long term side-effects of the vaccine.

This document answers many of the questions that emerged from the vaccine hesitancy survey. The information found within this document was taken from peer reviewed journal articles, the CDC website, and the FDA.

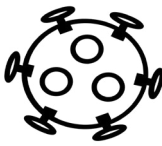
This information guide was created with funding from the CDC.

Written by Michele Knowlton-Thorne



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What is COVID-19?

COVID-19 is a virus but is not like the typical flu. In March 2020, the World Health Organization declared that COVID-19 was a global pandemic. A study comparing the COVID-19 cases between March 1 and April 30, 2020, and 5 previous flu seasons found that people who had COVID-19 were more likely to require ventilation (31 % vs. 8%) and more had a higher mortality rate once admitted to the hospital (20% vs. 3%). (Donnino, M. 2021)

What vaccines have been approved for COVID-19?

In the United States there are currently 3 vaccines that have been granted Emergency Use Authorization from the FDA. Those are Pfizer-BioNTech, Moderna, and Johnson & Johnson. All of these vaccines are given with a needle.

Do the Vaccines cost me money?

No. The vaccines are free.

What affect have these vaccines had on hospitalization rates and Mortality?

The Center for Disease Control (CDC) has stated that data from January to June 2021 in the U.S. suggested that 99.5% of COVID-19 deaths were unvaccinated people. A nation wide study conducted in Israel looking at the four months of their vaccination campaign showed that two doses of the Pfizer-BioNTech vaccine was 91% effective at preventing infection and 96% effective at preventing hospitalization and death (Hass 2021).

Where can I get the COVID-19 vaccine?

You can find a vaccination location near you on this website:
<https://www.vaccines.gov/search/>



What is the vaccine approval process?

Pre-Clinical Phase: Research is typically conducted on new vaccines in animals before they are tested on humans.

The vaccine approval process has 3 Phases in clinical development:

Phase 1: a small group of people receives the vaccine

Phase 2: a larger targeted population based on age and health take the vaccine

Phase 3: thousands of people are given the vaccine

Vaccines are given full approval after the Phase 3 trial is completed and has shown to be safe.

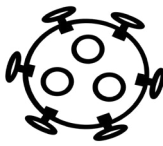
What steps were taken to ensure the safety of these vaccines?

Scientists followed the same steps taken for a typical vaccine approval process. However, a few steps were altered to accelerate the approval process.

Typically the testing done on animals is done before the vaccine is tested on humans. For the COVID mRNA vaccine, these tests were performed at the same time. The second change was in the timeline for Phase 3 of the study. For an Emergency Use Authorization to be given, patients in the Phase 3 portion of the study must be followed for severe adverse side effects for at least two months. (apnews.com)

When the Pfizer-BioNTech vaccine was granted Emergency Use Authorization, over 35,000 people had participated in the clinical development process.

Pfizer-BioNTech, Moderna, and Johnson & Johnson are the first vaccines that have been granted Emergency Use Authorization.

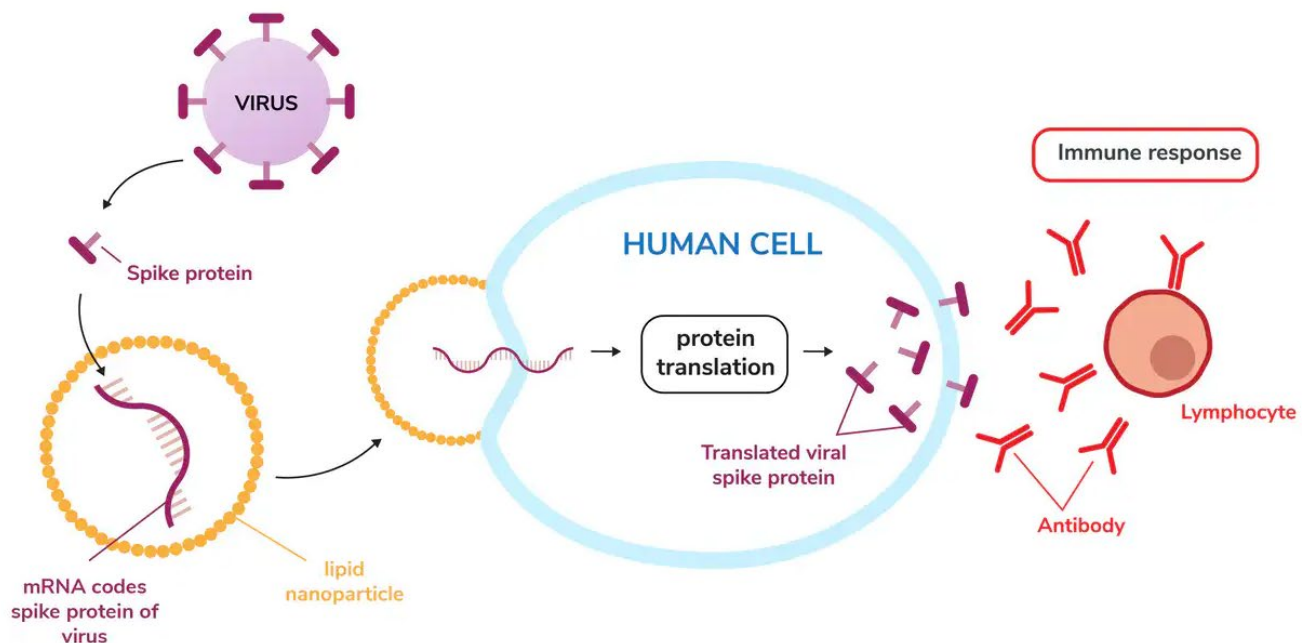


How do the COVID-19 mRNA vaccines work?

Pfizer-BioNTech and Moderna are mRNA vaccines.

The COVID-19 virus is round in shape and has projections that come off of its surface. These are called spike proteins. When your body encounters a foreign substance- like the COVID-19 virus, it produces an immune response to destroy that foreign substance.

The mRNA vaccine works by injecting people with the mRNA that contains instructions for the cell to produce the spike protein on the surface of the cells in their body that encounter the mRNA. The body's natural defense system will see those proteins as foreign substances and creates antibodies to destroy them. Those antibodies remain in your system, and if your body encounters that spike protein again, it can recognize it quickly and mark it for destruction before it can multiply in your body.



Messenger RNA vaccines get the recipient's body to produce a viral protein that then stimulates the desired immune response. Trinset/iStock via Getty Images Plus

- mRNA is made up of different nucleotides: adenine (A), uracil (U), guanine (G), cytosine (C)
- mRNA is a short-lived molecule that creates specific proteins.
- mRNA does not alter DNA- it never enters the nucleus
- mRNA does not cause infertility
- mRNA does not remain in your system for a long period of time- breaks down into its separate nucleotides within 20 hours- this is why the mRNA vaccine must be kept in such cold temperatures
- mRNA vaccine does not infect you with the COVID-19 virus



Is mRNA technology new?

Yes and no. mRNA technology has been around since 2010 and has been involved in Phase I, II, and III drug trials for various mRNA vaccines. The creation of and delivery of the mRNA vaccine from the needle and into the cell has been studied and experimented on for the past ten years. So even though we do not have any long-term studies on the COVID-19 vaccines, we do have long-term studies on similar mRNA vaccines, and those show positive longer-term safety outcomes.

If mRNA technology has been around for a few years, why is this the first time it has been used on a wide scale?

The reason comes down to two things; clinical trials and money.

To test a new vaccine it takes people willing to sign-up for clinical trials and it takes money.

It would also cost billions of dollars to alter the vaccination systems we have in place. The traditional vaccine industry has been in business for over 70 years. The complexes to support that type of vaccine production have been built and paid for. The vaccines produced traditionally cost less, are more stable at room temperature and have a proven track record.

To bring the mRNA vaccines to the marketplace on a massive scale, billions of dollars were required to develop that industry and allow for the transportation of the mRNA vaccines at low temperatures. (usatodaynews.com)

So why shift to mRNA?

mRNA is unique in that it takes several steps out of the vaccination production process. Traditional vaccinations require incubation in eggs. Then, the virus is put into the hen's eggs, and the eggs replicate the virus. The flu viruses are then killed and then purified. This process takes longer, has more steps than the mRNA vaccine, and therefore can have more errors during production. This process also takes a longer time to produce the vaccines; this is why scientists must guess every year which strain of the flu will be most prominent during flu season so they can make enough vaccines by the time the flu hits the United States.

The mRNA vaccine skips many of these steps by simply putting the blueprints for the spike protein directly into your cell. This means that as soon as scientists know what the blueprints are (mRNA sequence), they can immediately create a vaccine for it. According to Walter Isaacson's book *The Code Breaker*, it took Moderna 2 days to make the RNA sequence and only 38 days to ship off its first vials of the vaccine.

How does the Johnson & Johnson/ Janssen vaccine work?



Johnson & Johnson/Janssen is a viral vector vaccine.

A piece of DNA is placed within a harmless virus. When that virus is injected into your body, DNA enters the cell and then it is translated into the mRNA and the mRNA then makes the spike protein. The spike protein then induces an immune response.

Viral vector vaccines have been around since the 1970s. They have recently been used to combat the Ebola outbreaks in Africa, and have been studied for use on other diseases like Zika, flu, and HIV.

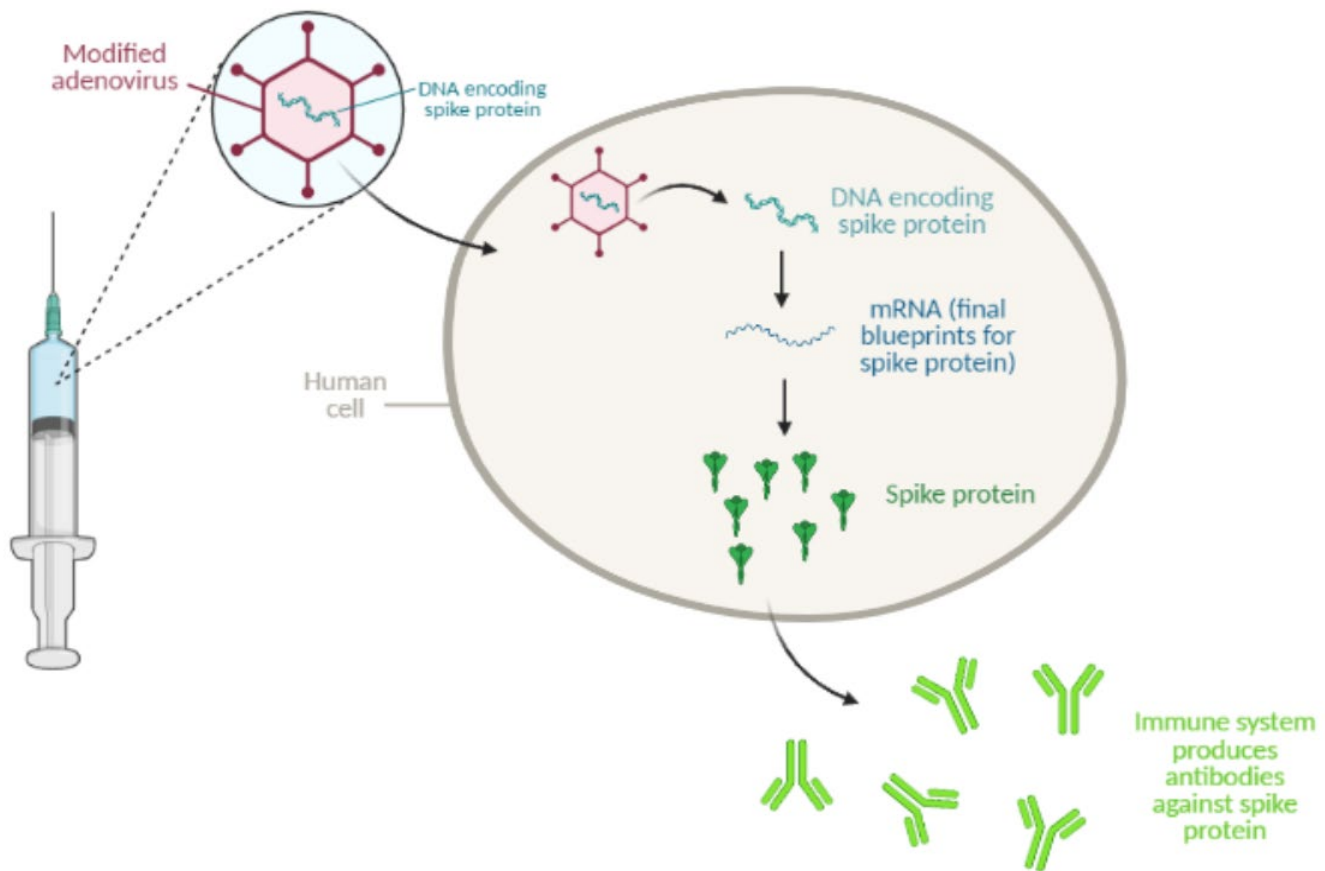


Image made using biorender.com

- The DNA code for the spike protein is cut and placed into a virus.
- The DNA enters the cell, is translated into mRNA, the mRNA makes the protein.
- The body reacts to the protein and leaves antibodies that are ready to respond to the COVID-19 virus.

(<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines/viralvector.html>)



What are the ingredients in the COVID-19 vaccines?

Ingredients included in Pfizer-BioNTech and Moderna mRNA COVID-19 vaccines

Description	Pfizer-BioNTech (mRNA)	Moderna (mRNA)	Janssen (viral vector)
Active ingredient	Nucleoside-modified mRNA encoding the viral spike (S) glycoprotein of SARS-CoV-2	Nucleoside-modified mRNA encoding the viral spike (S) glycoprotein of SARS-CoV-2	Recombinant, replication-incompetent Ad26 vector, encoding a stabilized variant of the SARS-CoV-2 Spike (S) protein
Inactive ingredients	2[(polyethylene glycol (PEG))-2000]-N,N-ditetradecylacetamide	PEG2000-DMG: 1,2-dimyristoyl-rac-glycerol, methoxypolyethylene glycol	Polysorbate-80
	1,2-distearoyl-sn-glycero-3-phosphocholine	1,2-distearoyl-sn-glycero-3-phosphocholine	2-hydroxypropyl- β -cyclodextrin
	Cholesterol	Cholesterol	Citric acid monohydrate
	(4-hydroxybutyl)azanediyl)bis(hexane-6,1-diyl)bis(2-hexyldecanoate)	SM-102: heptadecan-9-yl 8-((2-hydroxyethyl) (6-oxo-6-(undecyloxy) hexyl) amino) octanoate	Trisodium citrate dihydrate
	Sodium chloride	Tromethamine	Sodium chloride
	Monobasic potassium phosphate	Tromethamine hydrochloride	Ethanol
	Potassium chloride	Acetic acid	
	Dibasic sodium phosphate dihydrate	Sodium acetate	
	Sucrose	Sucrose	

Credit: CDC

These vaccines do not contain any aluminum or thimerosal. They also do not contain any tracking chips.

What are the side effects of the COVID-19 vaccines?

The most common side effects are:

Sore arm, fever, cold sweats, dizziness, and weakness which lasts 24-48 hours.

If you have a response to the vaccine, it means that it is working properly and preparing your body to fight the COVID-19 virus.

What are the risks of a COVID-19 infection on children in the disability population?



In assessing pediatric patients tested for COVID, Black, Hispanic, or Asian children were less likely to be tested but more likely to have a positive test result when tested. This report also indicated that those with Types 1 and 2 diabetes, malignant disorders, gastrointestinal disorders, genetic disorders, hematologic disorders, musculoskeletal disorders, mental health disorders, and metabolic disorders were more likely to have a positive test result. Severe illness was seen in 7% of the cases that tested positive, and the fatality rate was 0.2% (Bailey, C. 2021).

Another study found that 25% of children who were admitted to the hospital with COVID-19 were obese. They also found that 80% of the critically ill children from COVID-19 were medically complex and already had long-term underlying medical conditions (Shekerdeman, L 2020).

Another study reviewed the medical history of 48 of 108 pediatric patients who required ventilation and found that 75% of those children had documented co-morbidities, of which 23% had pre-existing cardiac disease (Williams, N 2021).

What are the risks of a COVID-19 infection on adults in the disability population?

People with intellectual disabilities are at greater risk of contracting COVID-19 and have a higher risk of mortality from COVID-19 compared to the general population (Gleason, J 2021). A whole nation study of Scotland found that adults with intellectual disabilities were twice as likely to get COVID-19, and 2.5 times more likely to die from it. (Henderson, A 2021). Another study showed that people with disabilities who lived in group home settings in New York during the first wave of the pandemic had a 15% case-fatality rate compared to a 7.9% rate for the entire state (Landes, S 2020). People with Down syndrome were also found to have a 4-fold increase in hospitalization, and a 10-fold increased risk of death from COVID-19 (Clift, A 2020). In another study that looked at the whole population of England found that those with chronic disease and those who had learning disabilities had a higher odds of mortality, with the exception of diabetes and hypertension (Joy, M 2020).

Why is this population at greater risk? Many in this community have co-morbidities which makes it more difficult to fight the virus. Many in this community also rely on other people to assist in their basic activities for daily living which means they can't quarantine as well as the general population. Others with severe mental illness aren't aware of the ongoing pandemic, and many with severe illness (75%) didn't report fearing contracting the virus (Kamalakanna, S 2021).



What are variants and how do the vaccines react to the variants?

Viruses can change as they move from one person to another. The original strain is called the Alpha strain, and as the virus mutates different strains are given different names. This can result in different variations (variants) of the virus. The changes can either have little or no effect or cause the virus to transmit easier and cause more serious infections.

The Delta variant is currently working its way through Europe and is believed to be 20% of the new viruses in the United States as of June 23, 2021. This variant is 60% more transmissible than the original strain.

Vaccine efficacy on the Delta variants:

Vaccine	Alpha	Delta
Pfizer	95%*	88%**
Moderna	94%*	N/A
Johnson & Johnson	66%	N/A

*Halim, Michael. Et al. COVID-19 vaccination efficacy and safety literature review. Journal of Clinical Medical Research 2021 (3) 1-10

**Lopez Bernal J, Andrews N, Gower C, Gallagher E, Utsi L, Simmons R, et al. Effectiveness of COVID-19 vaccines against the B.1.617.2 (Delta) variant (IN PRESS). New England Journal of Medicine. 2021.

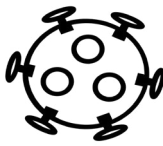
N/A- data not available

What are breakthrough cases?

Breakthrough cases occur when vaccinated people become infected with COVID-19. The vaccines for COVID-19 are very effective in preventing hospitalizations and death but they are not 100% effective. For example, if a vaccine has a 95% efficacy rate, then 5% of people who get vaccinated can still become infected with the virus they were vaccinated against.

What can you do if your child is too young to get the vaccine?

If your child is still too young to get the vaccine you should still have them wear masks when they are out in public. Child mortality from COVID-19 is extremely rare, but we are still unsure of how COVID-19 affects people long-term. To be safe, mask up.



How can you have a good vaccination experience?

A great place to start is with this [Guide for Caregivers](#).

Links to videos:

Let's Talk about the Corovavirus: [UMNSU CARD](#)

Fact's about the COVID-19 vaccine: [Autistic Self Advocacy Network](#)

Accessible video for people with learning disabilities: [Hft Learning Disabilities](#)

COVID-19 Vaccines and People with Disabilities: [DDI at WSU](#)

Links to social stories:

Getting a COVID-19 vaccine: [Rutgers](#)

Getting a Vaccine: [Howard County Autism Society](#)

How I get my COVID-19 shot- [CDC](#)

Talk to your doctor.

We understand that this document may not have answered all of the questions you have about the vaccine. If you are still concerned about the vaccine please talk to your doctor. You might want specific information regarding the risk and benefits of getting your child vaccinated when taking into account their disability. If your child has seizures, you might want to ask about the possibility of a fever induced seizure after your child gets the vaccine- and what steps you can take to prevent that from happening.



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